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Defining primary palliative care for universal health coverage

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Primary Palliative Care: essential for Universal Health Coverage and needing to be defined and developed.

Much has been achieved in getting palliative care onto the global health agenda over the last 5 years but there is more to do. The 2014 World Health Assembly (WHA) unanimously committed countries to integrating palliative care into their health systems and the WHO was tasked with monitoring progress.(1) By 2017, WHO had updated the definition of Universal Health Coverage (UHC) - Sustainable Development Goal 3.8 - to include palliation along with promotion, prevention, treatment and rehabilitation.(2) A Lancet Commission (2017) highlighted the global need to take action when 61 million people are living with serious health related suffering due to uncontrolled pain and lack of access to an affordable essential package for palliative care.(3)

The central role of primary care in delivering 'health for all' has been widely accepted since the Alma Ata Declaration in 1978 and the Astana Declaration of 2018 endorsed it further.(4) In 2019 the focus of the WHA in May and the United Nations High Level Meeting in October is on primary care led UHC and how this can be made a reality by 2030.

Changing population demographics and disease epidemiology mean people are increasingly dying from chronic non-communicable disease (NCDs) in low and middle-income countries (LMIC) after a period of poor health.(5) Primary care led chronic disease management which includes palliative care is essential to deliver cost effective UHC which does not impose financial hardship on people with NCDs.(2)

Palliative care for all is only achievable if all health care professionals who care for people with life-limiting illnesses deliver it. This holds true in all health systems regardless of a country's income status.(6) People are at home for the majority of their last years of life so primary care teams must provide much or all of the palliative care they need. Palliative care delivered by primary care teams is well developed in some higher income countries and the Primary Care Reference Group of the European Association for Palliative Care promote this with its recently updated Toolkit.(7) In LMIC, such models are mostly lacking although the 2018 WHO guidelines for introducing palliative care into primary care are a promising start. (8)

The current moves to achieve primary care led UHC including integrated NCD management, provide a real opportunity to ensure that palliative care is being delivered at the primary care level in all parts of the world and to exploit synergies between disciplines.

Palliative care sits comfortably within primary care. Both deal with a wide spectrum of illness, not limited to a single disease process. At their best, both recognise the importance of a holistic approach and coordination of care alongside person-centred care for patients and families within a wider context. The clinical competencies to achieve this are often lacking amongst health workers particularly in LMIC.(9) Incorporating a palliative care approach into primary care addresses health-related suffering in advanced illness while also facilitating development of core skills for primary care practitioners even in remote low income settings.(10)

Thus, the scope of palliative care within primary care is wide and its development vital to enable UHC. This needs to be recognised and clearly defined. We propose that 'Primary Palliative Care' is the internationally adopted term. Primary Palliative Care was first coined in the UK by Charlton's book on developing palliative care in primary care.(11) The term was consolidated in a 2004 article making the case for the benefits of delivering palliative care within primary care and the need for research and an academic base there.(12) However, whilst these publications set out the scope of Primary Palliative Care the lack of a clearly stated definition has led to some confusion.

In 2011, Weissman and Meier in USA defined Primary Palliative Care as "the basic skills and competencies required of all physicians and other health care professionals" and applied this to hospital practice.(13) This definition has subsequently been used in other seminal papers.(14) Whilst hospital professionals should also have generalist palliative care skills, to broaden the definition of Primary Palliative Care in this way loses its focus and leads to confusion. Primary Palliative Care (a subset of generalist palliative care) is better defined as "Palliative care practised by primary care clinicians, who are the principal providers of integrated health care for people in local communities throughout their life course. Primary palliative care includes early identification and triggering of palliative care as part of integrated chronic disease management, collaborating with specialist palliative care services (where they exist) and strengthening underlying professional capabilities in primary care."

A clear understanding of what the primary care workforce can achieve will facilitate strategic palliative care development and impact worldwide. Then integrated NCD management including palliative care as part of UHC will become a reality.

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